



Background and Survey
Methodology Information

on

The Report on the **Value of Caring**

Based on

The EUFAMI Caring Survey

carried out jointly by EUFAMI and the
Care and Policy Centre at the LSE

September 2020

The Report on the Value of Caring

Summary

This survey of more than 700 caregivers – sometimes referred to as informal carers – across Europe and Canada highlights the tremendous and too often hidden value of caregiving. Potentially without the input of these (mainly of close family) carers undoubtedly some of the supports would need to be provided instead by health and social care systems. In short, the functioning of many health and social care systems is very dependent on informal carers; it is critical, therefore, to invest in measures to support these caregivers and identify potential risk factors that might lead to a breakdown in caregiving support.

As part of the study a review of published literature was undertaken and found relatively few studies looking at carers of serious and common mental disorders, compared to studies focused on dementia caregivers. So, despite the importance of caring for carers and understanding the value of caring, more can be done to highlight this issue for policy makers. In the case of dementia, raising awareness of the value of caring has been very important; the increased focus on dementia over the last two decades has directly led to the development of supportive policies for dementia carers in many European countries. This survey and report aims to help change this for carers of persons affected by enduring and severe mental ill health.

Background and aims

Family and other informal caregiving is a fundamental contribution made to the welfare of all societies. We all rely throughout life on different levels of care and support from family and friends. Some of this caring is seen as a fundamental duty, this being most evident for parents providing care for their children until they reach adulthood. In this case many high-income countries provide financial help and other supports to help parents manage their caring responsibilities with some of their other activities such as going to work.

Yet too often for other groups that require care and support the same level of recognition of the value of care is not there. This includes family members and other informal carers supporting people with mental health problems that EUFAMI represents across Europe. These carers are an essential part of mental health support systems, but usually their contributions are not fully recognised, with insufficient support in many different countries for their own health and welfare needs.

EUFAMI's previous Caring for Carers Survey (C4C) revealed many challenges faced by carers. While there are positive experiences from caring, their survey of over 1,000 carers in 22 countries revealed that more than one in three carers had reached breaking point where they found caring difficult to continue, with high levels of anxiety. It also revealed that

caring often had a detrimental effect on the carer's own health, while around 15% of family caregivers felt they were treated differently because of the stigma associated with the mental health of the person they were caring for.⁽¹⁾

One critical step in changing this situation is to better identify and value the rewards and challenges associated with informal care in different country contexts. While reasonably well documented in respect of dementia, this is not well understood when looking at other mental health problems including anxiety and depression, bipolar disorder and psychoses. Take for example one parliamentary report in Canada, albeit written more than a decade ago, which stated that "caregivers feel excluded, ignored by the mental health, mental illness and addiction system in Canada. Ironically, it is these same family members who often provide most of the care and support to people living with mental illness."⁽²⁾

With this in mind EUFAMI in partnership with the London School of Economics and Political Science (LSE) conducted a new carer survey. It should be stressed that this survey is not an update of the C4C survey. Instead the aim is twofold, firstly to better understand components of the economic impact of informal care in specific country contexts. Secondly, to make an estimate the economic value of informal caring, and separately provide a simple tool that can be used to help refine estimates of the value of informal caring. In preparing this report a rapid review of the literature on the value of informal care was also undertaken.

Survey methods

A survey was developed in collaboration between LSE and EUFAMI. The challenge was to design a questionnaire that would be delivered online, although a paper version of the survey was available on request. It was also necessary to balance the need to obtain specific information to allow the researchers to estimate the value of care, with the risk of low levels of survey completion seen in longer surveys. The survey is therefore shorter than the previous (C4C) Survey. Based on a review of the literature and past experience in estimating the value of informal care, focus was placed on seven key themes.

- Value of time spent caring
- Loneliness
- Carer Quality of Life
- Participation in employment, leisure, education and volunteering
- Carer contacts with health services
- Impacts on finances and family life
- Use of health services by person receiving informal care

A priority was put on the order of survey questions in order to ensure that the most critical elements of the survey would be included in the analysis: basic carer and care recipient characteristics, time spent caring and its value, levels of loneliness and quality of life, and impacts on normal daily activities such as participation in employment and leisure were prioritised.

The survey included key metrics needed to accurately value informal care including self-reported estimates of time spent caring, as well as using a validated carer specific qual-

ity of life instrument developed in the Netherlands – the CarerQoL-7D – to measure of the impact of caring on carer quality of life. Carers are known to be at higher risk of loneliness compared to the general population, but there has been limited research looking at the experience of informal carers of people with mental health problems. We looked at the potential association between experiences of caring and levels of loneliness, measured using the brief 3 item version of the University of California, Los Angeles, (UCLA-3) Loneliness scale. A modified version of the Client Service Receipt Inventory was used to record carers self-reported use of selected health and social care services, including some specific carer supports, as well as caring-related travel time and expenses, over the previous three months. Some brief questions on contact with health services by people being supported were also included. Adapted versions of some questions related to the financial burden of caring from the previous C4C survey

The survey was administered via QUALTRICS, a secure online survey collection system that is compliant with GDPR. Ethical approval was provided by LSE and all responses were anonymous. Informed consent was required to participate in the survey, and critically respondents were free not to answer any questions they did not wish to answer.

To be eligible to participate respondents had to be, 18 years or old and caring for someone aged 18 years or older with at least one severe mental health condition (other than dementia and learning difficulties). They

did not have to be the main informal carer, nor live in the same household as the person they cared for. Carers were not eligible to participate if they were formally employed to be a carer, but they were still eligible if they received a social welfare benefit for caring.

The survey was launched online in September 2019, first in English and then adapted and translated into French, Spanish, Italian and Danish. Different country specific versions of the survey were available in English to cover the different contexts in the UK, Ireland, Canada and Malta. There were two French versions for Canada and France. Unlike the previous C4C survey that covered 22 countries our survey was tailored for and specifically targeted at eight countries that EUFAMI wanted to focus on: Canada, Denmark, France, Ireland, Italy, Malta, Spain & the UK. Respondents from beyond these eight countries were also free to take part in the survey but no active efforts were made to recruit these additional carers.

Recruitment to the survey was mainly dependent on awareness raising actions by EUFAMI and EUFAMI member associations through social media. This is a significant limitation of the analysis as in a survey of this type we are unable to apply probability-based samples methods, which means that respondents to this survey may not be representative of the target population. Indeed, many carers who are members of family associations may be more informed and have access to more support than carers who are not members of family associations. Our reliance on an online survey also

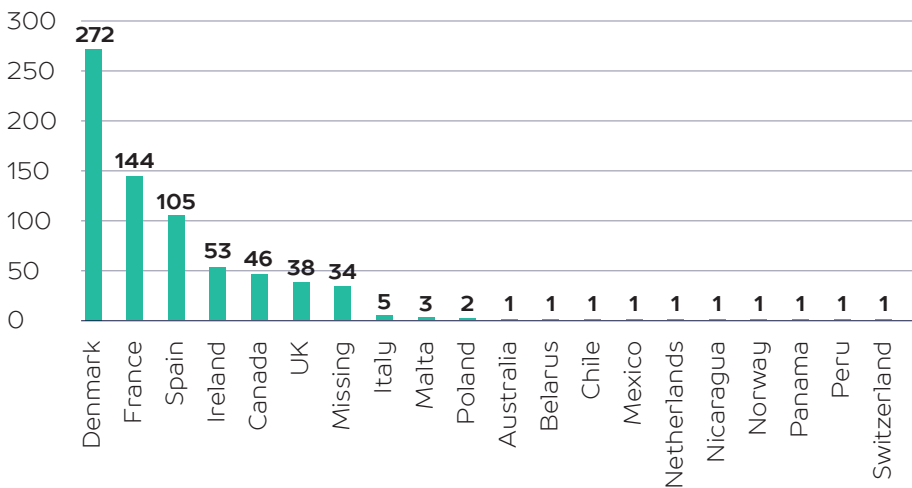
means that carers without these technologies, as well as those who are reluctant to use these technologies will also be missing. This means that the results of this survey must be treated cautiously and should not be interpreted as being representative of all carers.

Response overview

712 individuals gave their consent to take part in the study, with most responses received between 20 June 2019 and 31 March 2020. 12 responses were received in April

and May 2020. All were from Canada. We decided to include these even though territories and provinces in Canada began going into COVID-19 lockdown from mid-March. Responses from all other countries except one from France, were received before the end of February, so should not have been affected by the COVID-19 pandemic. 50.1% of questionnaires were fully completed, while 34 questionnaires provided no information other than consent. Survey respondents took a median 14.23 minutes to complete questionnaires.

Countries of informal carers



Potentially one reason for the low response rate in Italy may have been because the survey was not translated into German, as EUFAMI associates in Italy are in the German speaking regions of the country. 12 (2%) responses were received from other countries.

(1) EUFAMI. Caring for Carers Survey. Available at <http://www.eufami.org/c4c/>. Leuven: EUFAMI; 2015.

(2) Canadian Mental Health Association. Caring together families as partners in the mental health and addiction system. Toronto: Canadian Mental Health Association; 2006.